Best Practices in Self-Directed Services and Supports:
Key Elements Across the Intellectual and Developmental Disabilities,
Behavioral Health, and Elderly and Physical Disability Fields

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Introduction and Purpose

The Council for Quality and Leadership (CQL) enlisted the Human Service Research Institute (HSRI) to compile a set of standards useful for examining the quality of self-directed services and supports across a range of populations. The tasks included identifying: a) key processes or practices associated with successful delivery of self-directed services across developmental/intellectual disability, mental health, elderly and physical disability fields; b) key structures or design elements; and c) key quality of life outcomes. To these tasks, we have additionally identified several key principles associated with self-directed services and supports.

Upfront, we note that terminology for the concept of "self-directed" services varies dependent on the population being considered. Terms such as person-centered, participant-driven, self-directed, consumer-directed, stakeholder involvement, and person-directed are all used to refer to services and supports identified as necessary and useful by the person who needs them, and controlled and managed by that person. To avoid redundancy or confusion, this report uses "self-directed services" to represent all the various terms in use. Distinctions related to the different terms in principles, structures, processes and outcomes are presented, as needed, in appropriate sections.

Regardless of the population served, we postulate that a well-designed and implemented self-directed service system is one that: a) has strong principles to guide what is done, and how; b) has key design elements in place to support self-direction; c) utilizes best practices in delivering services and supports; and d) anticipates what people want to lead a full and meaningful life. This is illustrated in the accompanying framework.

Principles of Self-Directed Services
To Guide What Happens and How

Structures
Key Design and Policy Elements for a Self-Directed System

Processes
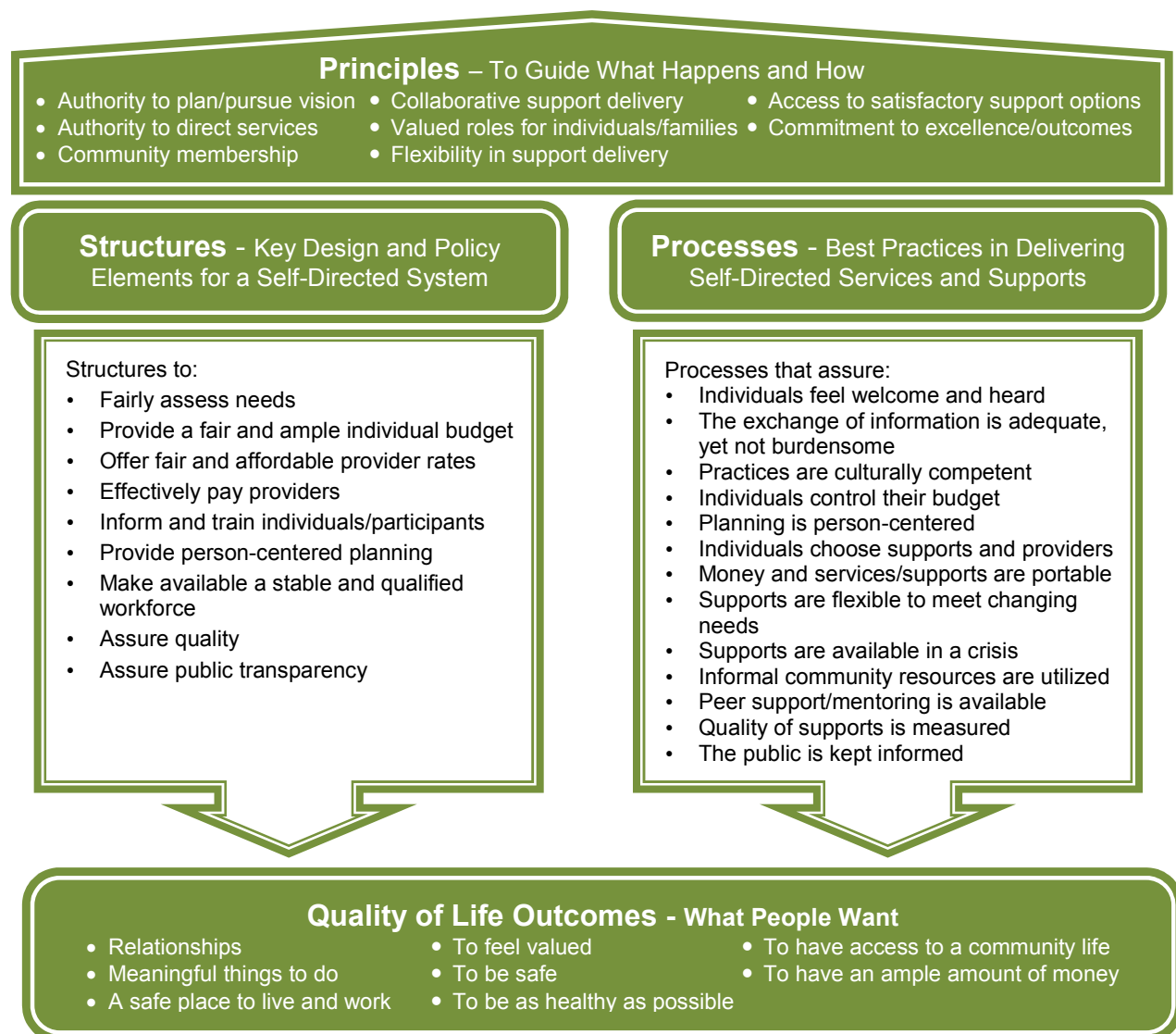Best Practices in Delivering Self-Directed Services and Supports

Quality of Life Outcomes
What People Want to Lead a Full and Meaningful Life

Methodology

We completed the following activities to synthesize current opinion on delivering self-directed services and supports across the areas of behavioral health, intellectual and developmental disabilities, elderly and physical disabilities, and to provide this overview. The activities include:

1. **Review of the Literature.** HSRI conducted a literature review to identify opinion on best practices in self-directed services and systems across the population areas. Materials were acquired from publications, website searches, online library resources, and HSRI-generated work in the area. A reading list of relevant resources is included in Appendix A.

2. **Interviews with Nationally Recognized Leaders**. HSRI conducted thirteen interviews with nationally recognized leaders/experts in three categories -- researchers, policy-makers and practitioners -- to elicit their opinions on critical elements for successful implementation of a self-directed model. A full list of these individuals in presented in Appendix B.

3. **Interviews and Focus Groups with People Receiving Services.** HSRI conducted two focus groups to identify suggested or actual best practice in facilitating self directed services and supports. One focus group included ten people with intellectual or developmental disabilities; the second group brought together ten individuals receiving supports through independent living centers, who represented a range of disability. Personal interviews were also conducted with 4 service recipients to elicit their opinions.

Findings

These efforts provided a wealth of information, across populations, across geographical areas, and across participation in the service system. In this paper, we present our findings using a framework that illustrates how overarching Principles (the values of a population) guide the Structures (key design and policy elements) and Processes (what happens and how), and

Principles – To Guide What Happens and How
- Authority to plan/pursue vision
- Authority to direct services
- Community membership
- Collaborative support delivery
- Valued roles for individuals/families
- Flexibility in support delivery
- Access to satisfactory support options
- Commitment to excellence/outcomes

Structures - Key Design and Policy Elements for a Self-Directed System

Structures to:
- Fairly assess needs
- Provide a fair and ample individual budget
- Offer fair and affordable provider rates
- Effectively pay providers
- Inform and train individuals/participants
- Provide person-centered planning
- Make available a stable and qualified workforce
- Assure quality
- Assure public transparency

Processes - Best Practices in Delivering Self-Directed Services and Supports

Processes that assure:
- Individuals feel welcome and heard
- The exchange of information is adequate, yet not burdensome
- Practices are culturally competent
- Individuals control their budget
- Planning is person-centered
- Individuals choose supports and providers
- Money and services/supports are portable
- Supports are flexible to meet changing needs
- Supports are available in a crisis
- Informal community resources are utilized
- Peer support/mentoring is available
- Quality of supports is measured
- The public is kept informed

Quality of Life Outcomes - What People Want
- Relationships
- Meaningful things to do
- A safe place to live and work
- To feel valued
- To be safe
- To be as healthy as possible
- To have access to a community life
- To have an ample amount of money

ultimately support individuals (service recipients) progress toward and achieve their personally-identified Quality of Life Outcomes.

Principles – Self-directed services must be guided by a set of values. These values, or principles, provide an overarching framework within which all structures and processes (i.e., policies, design elements and practices) are consistent. At an individual level, self-directed models value personal authority to plan for and pursue one's own vision for the future, and the authority to direct the supports that help individuals achieve their goals and meet their needs. Self-directed models recognize the value of community membership, and the potential for individuals to include families, friends, neighbors, co-workers and others as possible supportive and collaborative resources. At the systems level, self-directed models value flexibility to accommodate people's changing needs and preferences, meaningful leadership roles for individuals and families, accessibility to an array of support options, and a sustained commitment to achieving service excellence and individual outcomes for service recipients.

Principles of a Self-Directed System must value:

- <u>Individual authority to plan and pursue their own vision</u> - Self direction values and embraces the concept that the individual is in the best position to know what he or she wants and needs, and that the individual should have power over factors that can help them realize their vision. Individuals should have the authority to state clearly what they want, and have it be listened to and honored by others.

Interview Notes: Individuals do not want "pseudo power" – where a plan is developed but the regular mechanics of a system are applied without attention to the person's unique situation. For example:

- People with intellectual disability talked about being "in the system", being offered what is available whether it is what they want or not. Many feel they are offered choices from a menu rather than the freedom to craft supports uniquely relevant to their own situation.

- People who are elders worry they will have to take the word of others more experienced than they are about services. Many expect great disruption in their lives and assume they will be placed in a nursing facility if their personal needs become hard to manage. They express little control over these kinds of choices. For many elders, time to do long-range, comprehensive planning is not available – choices have to be made quickly to accommodate sudden problems. This means that planning structures need to be varied and responsive to the situations that arise.

- People using behavioral health services state they rarely feel they have (or are expected to have) any control over their own services, and feel frightened and alone when they find themselves in need of services

- People active in the independent living movement spoke passionately about wanting lives full of the same choices as the lives of people who don't have disability, including authority over decisions about having and raising children.

- Individual authority to direct services – Self-direction values individuals being in charge of what happens, what services and support you receive and who provides them. Self-directed systems should put real control in the hands of individuals, instead of with the programs and professionals. For this power shift to occur, the roles of professionals and individuals must be redefined. Professionals must believe that individuals are capable and willing to make the best decisions for themselves, and accept their role as a supportive partner who assists the individual when asked, and in ways the individual requests.

- Community membership – Self-direction values and promotes inclusion and participation in a community, recognizing that "promoting community membership" represents something different for each person. For one person, this might mean preserving an existing community (network of friends and family) as one enters into the service system, while for another it could entail creating opportunities to develop new relationships. Regardless, across the lifespan, a self-directed model recognizes that individuals must be supported in developing and sustaining their social relationships, including friendships, family connections, religious affiliations, and romantic relationships.

> Interview Notes: Individuals talked about community from a variety of points of view, but made clear that the definition needs to be personal. For example:
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> - A gentleman with physical disability said that for him, the community is his house and a few good friends. He wants nothing to do with having other connections to clubs and interest groups, let alone opportunities to participate in the mainstream of community.
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> - Some people with intellectual disability are worried that community membership means that they all have to do the same things, harkening them back to times when they lived in an institutional setting and never functioned independently.

- Collaborative support delivery – Self-direction values personal networks of individuals, friends, family, co-workers, neighbors, and others, and connects service delivery systems with these "individual communities" to support individuals in achieving their goals. Self-directed models must seek cohesive responses to need, rather than sorting needs into neat categories and assigning responsibility for meeting needs to this or that public agency. Individuals must be supported to negotiate across several service silos, to effectively weave together their needed resources.

- Meaningful leadership roles for individuals and families – Self-directed models value and assure meaningful leadership roles for individuals at all levels of the service system. Leadership at the individual level is assured through personal authority to plan and direct services (see above), yet it must also be incorporated at the service delivery and systems level, collaborating with and supporting individuals to participate meaningfully on decision-making and policy-setting boards. Within each population, it is also appropriate to seek similar meaningful participation from family members (e.g., parents, spouses, children). A self-directed model recognizes that families support individuals of all ages, and while some individuals choose to disassociate from their families, others rely heavily on their families for support and advocacy.

- Flexibility in support delivery – Self-direction constantly refers back to what the person needs and wants. People change, their needs and desires change, and a self-directed model can bend to accommodate these changes. Services and supports can be customized around the particular needs and preferences of the individual. Self-directed models recognize that there are alternative pathways to achieving individual goals. This flexibility also speaks to the availability of intermittent supports, that is, supports that can be arranged when they are needed and disappear when they are no longer relevant.

- Access to satisfactory support options – Self-direction means that people not only have the power and authority to make support choices, but also that there are options available to them that are appropriate and desirable. If services are inaccessible, due to barriers in physical structure, geographic location, language or culture, people might not be able to, or might not want to, use them even if they are needed. Essential to a system of self-directed supports is an array of choices that are real, that are available and appropriate to the needs and desires of the person.

> Interview Notes: Individuals desire an improved level of access as a baseline, across the entire community. Commitments to increased physical, linguistic and cultural access should be a foundational element in all planning that takes place. Beyond that, several of the interviewees had specific comments. Examples include:
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> - An elder who said that she used to be able to do whatever she wanted, but now, because there are town buildings where she lives (that she cannot get into), she feels her presence is no longer welcome.
> - A mother interviewed said that the specialized services she needs for her young teen with significant behavioral health issues don't make sense to her, because such services aren't typically part of the way her culture views her sons' disability.

- Commitment to excellence and personal outcomes – Self-direction values and assures a sustained commitment to achieving service excellence and individual outcomes for service recipients. A commitment to service excellence is evidenced in a highly skilled and trained workforce, consistent high quality services (across time and geography), easily accessible information and education for service recipients, and ongoing mechanisms for quality improvement. A commitment to personal outcomes is evidenced in services that support a future determined by the person him/herself. Since both significant effort and funding may be used to move toward the goals that the person designs, self-direction is not about whim, but rather speaks to engagement of the individual, and whatever services are employed to support their personal goals.

Structures – Structures are the key design and policy elements essential to a self-directed system. The connection between structures and processes is inextricable. That is, each process or best practice must sit within a structure that not only allows for, but promotes its availability and opportunity to be implemented successfully. The key structures presented below assure system effectiveness and efficiency, adequate education to assure meaningful participation, individual leadership and public support, and the necessities to assure continuing quality.

Structures in a Self-Directed System must:

- Fairly assess needs – Essential to the effort of a self-directed system is having an assessment measure that provides sufficient information to differentiate among service participants accurately and reliably with respect to their support needs. It is also essential in a self-directed system, for the later purposes of developing an individual budget, that the measure selected be capable of reliably assessing support needs as well as the relationship between these needs and dollars expended. This structure is also separate from the person-centered planning structure, where individual goals and preferences are developed based on the allocated budget as well as other resources available to the individual. Imperative to the self-directed system is the assurance that individuals meaningfully participate in determining which tool is used at a systems level, and of course, how need is assessed at the individual level.

- Provide a fair and ample individual budget – While all of the resources necessary for achieving the person's desires may not be available, knowing what is available and having options for using those resources, puts control into the hands of the person where it belongs. Knowing one's allocation can improve supports planning, especially when coupled with an assessment measure that assesses support needs. The Supports Intensity Scale, for example, was designed originally as a means of informing service planning. It covers a range of topic related to daily living skills, community life, employment, medical needs and behavior. When an instrument such as the SIS is used to build individual budgets, the findings may also be used to help build support plans, or at the least spur discussion on various life topics. In addition, with a personal budget based on the assessment, individuals can better consider their needs in relation to the size of the budget and the supports available to make well planned decisions about what services they choose. Simply having an individualized budget, however, is not sufficient. The budget must be ample enough to purchase the supports needed. And the system must support individuals to understand how much money is available to them, how it was derived, and in what ways it can be used.

- Offer fair and affordable provider rates – Central to a self-directed model is the fundamental principle that a state's payments for services should ensure that each provider of a service receives sufficient compensation to support the delivery of necessary services to each individual. Payments for community services should be scaled to take into account assessed differences in supports needs based on a standardized assessment of such needs while promoting the economical and efficient delivery of services. The service rates themselves are graduated to take into account differing intensities of support needs exhibited by individuals, as well as other potential factors (e.g., policy preferences pertaining to allowed indirect expenses, emphasis on allowed expenditures for staff training or health insurance for staff). The budgets people are awarded must be sufficient to purchase the services they are meant to pay for. And providers must likewise be reimbursed sufficiently for the services they deliver.

- Effectively pay providers - Payment structures that are reasonable, fair, and appropriate for providers of supports or services. As a wide range of supports are developed, providers should be able to expect reimbursement for services rendered in an appropriate time frame and with reasonable requests for documentation.

- Inform and train individuals/participants – In a self-directed system, individuals have authority over how their budget is applied to meet their needs, choose from an array of

services and supports, and choose and manage providers. Therefore, a structure must be in place to assure that needed supports are available, so individuals can participate and lead effectively to their full potential. The level of support, information and education will vary with each individual, may be needed intermittently, on a regular basis or not at all. But a self-directed service model cannot presume that individuals can play a leadership role within this system without training and support. Support may come from peers, family members, friends, case managers and/or others.

Difficulties must be anticipated and addressed. For example, practices within a self-directed system (e.g., service planning, managing staff) can be made so complex that people are unable to participate without significant intervention from others, and so, authority shifts from the individual to others. Policy makers must take steps to simplify practices, work at making requirements easy to understand and satisfy, and provide impartial supports to individuals when needed. For instance, fiscal intermediaries can manage paying staff, tracking expenditures and other paperwork responsibilities without undercutting the individual's want to direct their own life. Other areas of information, training and support include:

- o Financial literacy support. Management of financial resources is a struggle for many Americans, individuals with disabilities, behavioral health needs, or elderly not excluded. Giving people the power to manage their resources is useless unless they can also acquire the information, skills or supports needed to manage those resources. Financial literacy involves an understanding of where money comes from and how much is available (for instance, earnings and benefits), how much things cost and where money goes (e.g., rent, services and supports, groceries), and how much is left (savings). It also involves account balancing, an understanding of credit and contracts, and other money management basics. A self-directed system must assure that information (e.g., on support costs), and training and support are readily available and easily accessible, so that individuals may direct the level of control they have over the mechanics of budget management.

- o Information on benefits. Public benefits, generic and disability specific, are complex structures. Individuals want to know that the process for determining benefits is handled consistently across time and individuals. To be fully (or adequately) informed, individuals must know what benefits are available, for which they might be eligible, and the steps for accessing appropriate benefits. This information, as with all information in a self-directed model, must be easy to understand and access. Benefit planners must also be available to support individuals, as requested, to navigate these complex benefit systems.

- o Information on service options. Individuals need clear, accurate, comprehensive and user-friendly information about the services and supports available. Choice is not about selecting from a menu; rather it is about looking at what is available, selecting what matches individual need, and also having opportunities to look outside "the system" for support options, or if not available, to create new options that are personally unique.

- o Information on planning. A self-determined system offers continual training in person-centered approaches. Training must take into account the different experience that people will bring to the concept of person centeredness. It must be flexible in finding ways to support the person as he or she creates the process that

will work for him/her, and it must make available information on best practices in implementing person centered planning so that everyone engaged in self-direction will have access to the best guidance possible.

- o Self-advocacy support. A self-directed model assures individual leadership at all levels of the system. With regard to system-level leadership, participation by willing individuals in advisory and decision-making capacities throughout the system will ensure the system's responsiveness to both strengths and problems that need to be solved. Individuals participating in policy-making and funding decisions must be supported, as uniquely needed and requested, to fully meet the obligations of these leadership roles.

- Provide person-centered planning – A self-directed system provides a structure for consistent and productive person-centered planning practices. A quality person-centered plan articulates an individual's personal vision for the future, incorporating goals tied to home, work, and social outcomes, as defined individually. It identifies individual strengths and needs, available public and community resources (including financial resources, paid services, and natural or unpaid supports), action steps for achieving personal outcomes, including supports needed. The planning structure enables the person to choose who, if anyone at all, should be involved in helping to plan or realize supports. It is flexible to allow individual participation only, or broad participation of others (selected by the individual). The system is flexible to encourage creative opportunities for partnerships and support, and it provides ongoing training for both professionals and individuals in the person-centered planning process and the role of natural and community supports.

> Interview Notes: Individuals do not want to take part in a "canned process", and many people interviewed voice strong concern over the way service systems embrace new practices, and then corrupt them. For example:
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> - One person interviewed with intellectual disability spoke about his individual service plan, saying that he thought it was supposed to focus on him. He doesn't think it does.
> - One elder interviewed is afraid that "person centered planning" is another way of saying, "make a change in your life," when all he needs are increases in personal assistance.
> - One person with physical disabilities cautioned that self-direction not become "the next new best thing".

- Make available a stable and qualified workforce - Negotiating and taking full advantage of the complex systems of services can be challenging and sometimes overwhelming. Confidence in the quality of the provider system to bring state of the art practice to the lives of the people it serves is essential. Equally essential is access to someone who can help with managing, brokering, and finding appropriate services and supports. This skilled management assistance enables fully informed choice making and inspires confidence that the process, from identifying need to receiving supports, is planful and organized. A well-trained, stable workforce is central to assuring the quality of services. When community agencies experience problems in recruiting and retaining direct support professionals, major problems are encountered in assuring quality. Many quality problems

are directly traceable to workforce problems. Workforce stability and quality is promoted when direct support professionals are skilled, receive adequate training, are paid sufficiently (with benefits), are afforded the flexibility and authority to support individuals creatively to meet their needs, are provided opportunity for career growth.

- Assure quality – Quality assurance in a self-directed model is both systematic and comprehensive. Useful information can be gathered by looking at details as well as by looking from a more general perspective. Treating an entire system fairly requires processes that examine both detail and the "ten thousand foot view". From a system perspective, it is essential that a state operate effective quality assurance/quality management systems that ensure that participating individuals are safe and secure and the services they receive meet essential standards. People with developmental disabilities, physical disabilities, behavioral health concerns and the elderly are particularly vulnerable to abuse, neglect, and exploitation. Consequently, it is important that their health and welfare be monitored. Individualized safety plans that do not compromise personal authority are utilized to minimize risk and monitor personal security. Best practice in quality assurance/quality management now includes the operation of data systems that are capable of pulling together information about the results of quality assurance processes to identify the extent to which problems are being discovered at the provider and system levels. Such data systems must have the capability to integrate quality information. For example, the results of routine monitoring of services should be linked to information gleaned from periodic provider agency quality reviews.

  Quality must also be looked at from the individual's point of view. For example, quality for an individual may focus more on having personal autonomy, feeling valued, using resources in a personally determined way, being satisfied with supports, and achieving personal outcomes. A self-directed model considers health and safety safeguards that are tailored to individuals directing their own services, such as assuring easy access to background checks for support providers, opportunities to address issues that arise in background checks, and opportunities to examine the outcomes of particular choices. Data collection and analysis here too is essential Data enables individuals and interested others to track what's happening, to understand how funds are being spent, to monitor movement toward outcomes that the individual values, and to identify areas in need of further scrutiny.

  > Interview Notes: A particularly poignant example here was provided by a director of an independent living center about the importance of personal authority in measuring quality. He said that when he hires a babysitter, with his own funds, the only arbiter of quality is himself. Very simply, if he likes the care that the babysitter provides, he would decide to hire her again. While this lack of external monitoring may not be feasible when public funds are used, he feels strongly that the person receiving the services should have the strongest voice in who provides the service, including whether criminal records checks should be done.

- Assure public transparency - Self-directed models are particularly open to public and legislative criticism concerning appropriate use (and potential abuse) of public funds. Therefore, it is imperative that the system maintain a mechanism for assuring ongoing transparency.

Processes – Self-directed models must employ current best practices to deliver services and supports to individuals. Across fields, self-directed models universally include key practices such as a person-centered plan, an individually determined and controlled budget, a qualified workforce and a method for assuring quality of services. Equally important, though, as *what* happens in a self-directed model, is *how* things happen. Current opinion dictates that self-directed services must also happen in a way that respects individual expertise, honors individual choice, responds to cultural differences, fosters community connections, and promotes flexibility, portability and accessibility. Recognizing that some individuals may not wish to take on all responsibilities within a self-directed model, it is still in the individual's control to determine which responsibilities they retain, and which they delegate to, or share with others.

Please note the term "service provider" and "provider" are used below to encompass both individual service providers (e.g., personal care attendants, therapists) and service providing organizations.

Processes in a Self-Directed System must assure that:

- Individuals feel welcome and heard - Individuals should feel welcomed by case managers and service providers, listened to, supported in their decisions, and not pre-judged. Individuals are the experts when it comes to their own lives. They know their strengths, preferences and needs. They expect their opinions to be heard, respected, and acted upon.

- The exchange of information is adequate, yet not burdensome - Information is power and it flows in two directions. Individuals need timely and up-to-date information about their specific disability, about appropriate services and supports, and about eligibility requirements in order to make decisions about meeting today's needs and planning for the future. This information should be offered freely and without hassle, and should be presented in a way that is easy to understand. Service providers also need information about the individual. However, individuals should only be asked questions that are relevant (i.e., the questions do not unnecessarily invade their privacy), and requests for information should not be over-burdensome (i.e., the burden of supplying information exceeds the benefit of services/supports offered).

- Practices are culturally competent - No two individuals, families or supportive networks are exactly alike. The meaning and structure of a "traditional" family have evolved and must be addressed in a culturally competent manner. Regardless of age or disability, household configurations and dynamics will be unique for each individual. Likewise individuals will vary in their ethnic origins and primary languages spoken, pressing service systems to accommodate varying languages and customs. And some individuals may be very difficult to reach, living in rural areas, or urban areas that are hard to penetrate. Self-directed systems, individually referenced and individually controlled, are respectful and culturally competent in anticipating and responding to the goals, needs and preferences of individuals across cultures, traditions and beliefs.

- Individuals control their budget allocation – Self-directed service delivery methods position the individual to manage a service budget, including distributing the budget among different types of supports and serving as the employer of service workers. Self-direction gives individuals a greater degree of control over services while concurrently encouraging them to seek out the most economical services. The amount of an individual's funding (sometimes called Individual Budget Allocations or IBAs) is determined by taking into

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account consumer characteristics, support needs, and usual and customary expenditures for people who have similar characteristics and support needs. The assignment of individual budget amounts creates a framework within which person-centered plans can be developed without sacrificing budget predictability.

- Planning is person-centered - Self-directed service delivery means that services and supports are identified and authorized to address the specific needs of each person based on an individualized assessment and through a person-centered planning process. Such planning places the individual in the lead so that each person can express what he or she wants in life and make decisions about the supports that will be employed to achieve the goals in the plan. Person-centered service delivery requires flexibility in both service selection and service delivery methods. Person-centered planning serves as the critical, instrumental tool for identifying the best mix of paid services and unpaid supports that will assist each individual in securing valued outcomes while concurrently assuring health and welfare.

- Individuals choose and manage supports and providers – Self-directed models offer choice among an array of services and supports, and are equipped to support individuals in obtaining needed supports beyond those in the array. Support services reinforce the strengths of the individual and build on strengths in the community rather than foster dependence on the agency providing supports. Individuals can freely select among all qualified providers and can readily change providers when dissatisfied with provider performance.

- Money and services/supports are portable – In a self-directed service system, the funds that are available to support a person are not locked into specific service models or locations (within a state). They are connected to the individual. For example, funding for residential services are not tied to particular types of settings but may be used to purchase services and supports in a variety of settings. Likewise, individuals relocating can expect their budget to retain their individual budget allocation, and service/support options (recognizing the potential need to identify new providers).

- Supports are flexible to meet changing needs – A self-directed model assures that service and support planning, delivery and funding is flexible to respond to changes in circumstance and need across the lifespan. Self-directed service delivery recognizes that there are alternative pathways to achieving individual goals. Regardless of the array of services on the official list, the attitude toward individuals in these systems is, "You tell us what you need and we'll support you to get it." The most progressive programs see their mission as stretching the limits of the "system" to the extreme for individuals. Services and supports are customized around the particular and changing needs and preferences of the individual.

- Supports are available in a crisis – Self-directed service models must anticipate and be prepared to effectively respond to potential crises in a respectful and individually-directed manner. While it may be impossible to anticipate a crisis, it is essential that individuals have opportunities to provide advance directives about how to respond to their own crisis. To the extent possible, potential crises must be anticipated and addressed or planned for (e.g., the aging or death of a loved one or caregiver, the collapse of a support network). Also, across populations, there are individuals who have extraordinary medical and/or behavioral challenges. A measure of the effectiveness of a service delivery system is the extent to which these challenges are effectively addressed within the community without

resorting to short or long-term hospitalization or institutionalization. Strategies for addressing such challenges include the operation of crisis networks and the development of centers that can provide clinical expertise to community organizations in addressing medical and behavioral challenges.

- Informal community resources are utilized – Self-directed models place individuals at the center of a support response, and ripple outward, allowing individuals to follow a natural path to support – starting close and informal, and branching out to more formal or structured service options. To the individual's choosing, self-directed models incorporate supports and resources closest to the individual (e.g., friends, family, neighbors, co-workers, church members, other informal and generic community resources), as well as public service opportunities. Self-directed systems seek to discover and utilize every capacity within one's community, recognizing that one of the strongest assets any community has is its people and array of community serving entities, such as churches, schools, colleges, businesses, libraries, neighborhood associations, clubs, recreational entities and other community serving organizations. Self-directed systems must seek to forge reciprocal alliances with individuals and the vast array of community assets available to find additional means for supporting people and their families.

- Peer support/mentoring is available – Self-directed models assure the availability of peer support and mentoring options. Peers can often provide instant street credibility, a counterpart with similar life conditions and/or experiences. By listening empathetically, sharing personal experiences and offering ideas, individuals are uniquely able to help others like themselves. This approach assumes, for instance, that people who have experienced a disability can better understand and relate to others trying to deal with a similar disability. Additionally, it promotes a social model which considers individuals with disabilities to be contributing members of society, as opposed to a medical model which considers individuals to be ailing. Peer support programs may differ in their approach, using peers as counselors, advocates, community connectors, tutors or simply visitors. They may also differ in whether peer support is an individual or group-based activity, and whether peer mentors are paid or volunteer. Regardless, many individuals value peer support and mentoring, viewing the common experience as useful, and the opportunity to reinforce one's own voice as attractive.

- Quality of supports is measured – Self- directed models should routinely and systematically ask (and respond to answers from) the question, "Are you better off for having participated?" This question is at the core of an individual's estimation of the services and supports s/he receives. Qualitative and quantitative mechanisms must be in place to assess satisfaction with services and supports, both individually and in the aggregate. Quality measures must be tied to individual outcomes. Individuals, families and advocates must be partners in evaluating services and providers, complaint and grievance procedures must be easy to understand and use, and quality assurance must involve an ongoing feedback loop, committed to achieving service and support improvement and excellence.

- The public is kept informed – To educate and inform the public, policy-makers included, about the use of public funds for self-directed services and supports, clear and simple reports to the public regarding individual needs and outcomes (in aggregate), budget allocation strategies, and assurances for service quality and economic efficiencies should be easily accessible.

Quality of Life Outcomes – The delivery of self-directed services should result in the achievement of valued outcomes for individuals. When services and supports are targeted and customized around the needs and preferences of individuals, better outcomes are achieved. In fact, the outcomes that a system can achieve are affected by the services that the system offers, the allocation of resources within the system, and the extent to which a system promotes the achievement of valued outcomes. Therefore, it is imperative that a self-directed system know or anticipate what people want to lead a full and meaningful life. These outcomes can then drive development of appropriate structures and processes, rather than be driven by them. Personal outcomes are as unique as the individuals themselves, yet common themes certainly exist across populations. In general, individuals want relationships, meaningful things to do with their day, to feel safe, to feel valued, to be as healthy as possible, to have access to a community life, and to have an ample amount of money to live modestly.

- Relationships – Too often, the stigma of disability, mental health issues, poverty and age leads to social isolation, and/or poses difficulties in forming or maintaining relationships. People want to feel connected to others, to experience friendships, relationships, and a sense of belonging (within a family or otherwise). These relationships must represent what is important to the person him/herself. For some, it may be a wide network of casual relationships, while for others, fewer more significant relationships are important. Individually-defined, people want to be supported to participate in social relationships, religious activities, recreational opportunities and other community-oriented activities. They want opportunities and support to develop new relationships, maintain existing relationships, and shed unhealthy or unwanted relationships.

- Meaningful things to do – People want a meaningful life, and to spend their time in meaningful ways. What determines "meaningful" is once again individualized. In general, it relates to purpose-driven activities, that is, activities that serve a purpose of bringing income, joy, satisfaction, knowledge, enlightenment, or a sense of worth to the individual or others. For many, this could include working, volunteering, traveling, taking educational or recreational courses, socializing or pursuing hobbies. People find that having something to do during the day that matters is essential to feeling that their life matters.

- To be safe – People want to feel and be safe. This includes having a safe and stable place to live, a safe place to work, and a sense of personal security. Individuals want to live in a home and neighborhood that is physically safe (i.e., one that is free from harmful environmental factors, low in crime). They want to feel confident that are not being taken advantage of by service providers or others in the community. They want stability in their home and work (or non-work) lives, and they want choice and opportunity to take risk. Personal direction, ample resources, a quality assurance system that emphasizes personal satisfaction and provider safeguards (all key components of a self-directed model) support the fruition of safety-related outcomes for individuals.

- To feel valued – Individuals want to be valued in their personal relationships, relationships with their communities and within society as a whole. They seek true decision-making power over issues that are important to them in their lives. They want their opinions and ideas to be heard and respected. They want to be engaged in their communities, and viewed first and foremost as a citizen within their community. Individuals want to be valued throughout their lifespan. The opportunity to hold a valued social role, close to home or within society at large is crucial.

- <u>To be as healthy as possible</u> – Individuals want to be as healthy as possible (given their specific age or disability) and supported to create or maintain a healthy lifestyle. Individuals want to be adequately informed to make choices about their own health, and when opportunities for improving health exist, individuals want ready access to those resources (e.g., medical services, medications, assistive technology).

- <u>To have access to a community life</u> – To be a full participant in community life, one must be assured access. Individuals want their choices to live an inclusive community life to be individually accommodated physically (e.g., transportation, physical access to buildings and parks), linguistically (e.g., ready access to interpreters and translators), and culturally competent (e.g., public and community supports that are culturally responsive).

- <u>To have an ample amount of money</u> – Many people with intellectual and developmental disabilities, physical disabilities, behavioral health issues and/or those who are elderly experience short or long-term poverty. This poverty affects individuals' sense of themselves and their ability to "make their way in the world". For some, economic security means knowing more about the benefits to which they are entitled or eligible, and being able to manage them. For others, it means having the same chance to hold down a meaningful job as someone who does not have a disability. And for others yet, it means moving into retirement not worried that their plans for economic security in their later years will fall apart.

Appendix A: Reading List of Self-Directed Resources

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